

It is private and confidential

This research project has been given approval by the Women's & Children's Health Network Human Research Ethics Committee. The Committee's Secretary, Ms Brenda Penny can be contacted on 8161 6521 if you wish to discuss the approval process or have any concern or complaint. The project is funded by the Channel 7 Children's Research Foundation.

When we publish the report or talk about the results of this research we will talk about what happened overall. We won't report anyone's results individually and we won't use your name in any publications or other documents.

Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applied to information collected in both research and non-research situations. Such requests to access information are rare; however we have an obligation to inform you of this possibility.

Thank you for helping us to understand and measure the physical activity experiences of young people living with ASD.

Can I change my mind?

Participation in the project is completely voluntary (your choice and your child's choice). You and/or your child can change your mind about taking part without giving a reason at any time (before December 2019). The Novita services that you receive will not be affected if you choose not to take part, or if you decide to stop taking part in the project.

Will I be able to find out the results of the project?

The research project will finish in December 2019. We will send you a summary of the overall results in 2020 and you will also be able to find information on the Novita website and on our social media channels. You can also get in touch with us if you have any questions.

Any questions?

If you have any questions about the project or are interested in being involved, please contact Dr Annemarie Wright. Her phone number is 08 8243 8281 or you can email her at annemarie.wright@novita.org.au

Call 1300 668 482
novita.org.au/autism-research



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Evaluation of advanced motor skills of school-aged children living with Autism Spectrum Disorder

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About the research project

This project is about finding the best way to measure the motor skills of kids and young people living with Autism Spectrum Disorder (ASD). A group of therapists and researchers from Novita will run the project.

Why is this important?

Exercise and an active lifestyle have important physical and mental health benefits for kids and young people. Young people living with ASD are sometimes less active than their friends or siblings. They may also need support to undertake the physical activity they need. Many young people living with ASD have difficulties with actions like running, balancing, coordination, or planning different movements. These actions are called **motor skills** and are important for everyday activities as well as in play and sporting activities. We know that motor skills can improve with different types of intervention or therapy, which can also help improve a person's physical health and fitness. There is early evidence that being active also may help decrease sensory and repetitive behaviours.

There has not been much research done on how to best measure advanced motor skills (activities like throwing and catching a basketball or running fast around cones) for young people living with ASD. Knowing what a child's motor skills strengths and challenges are could help those who work with them to provide well-targeted interventions. A measure of motor skills will also provide a way to find out how a child's motor skill abilities change over time. The **Ignite Challenge** is a new assessment, developed in Canada by one of our team members, that provides a new way to measure advanced motor skills in kids and young people living with ASD. The **Ignite Challenge** is already used at Novita and in Canada and we know it is safe and fun for young people to do. This research project will help us to find out if it is as good a measure as it can be, and whether it works equally well when different physiotherapists use it.

We also want to know what it is like to take part in doing the **Ignite Challenge**. To figure this out, we will ask for feedback from young people and physiotherapists about what they liked and what they didn't like about the assessment and how it was used. We will also ask them how the information learnt from the assessment could be used to help them in their goal setting and physical activity planning. In addition to guiding any changes to the **Ignite Challenge** testing process, this feedback will help us to make a user guide for physiotherapists and sports coaches. We hope the user guides will help them with goal setting and community participation for young people living with ASD.

What will my child have to do?

If you and your child take part in this project we will ask you to attend two study sessions at a Novita office. We will work with you and your child's Novita team to make sure that they understand what will be done and that we know the best way to set up the assessment so they feel comfortable before and during each Novita visit.

Session One



The session will take about 45-60 minutes.

A Novita Physio will guide your child through the **Ignite Challenge** and the session will be videotaped so the Challenge can be scored.



The **Ignite Challenge** involves 13 mini-games like running down a special track and stopping fast, doing a bounce / catch sequence with a ball, as well as some fun balance and jumping skills.



During the first session while your child is doing the **Ignite Challenge** we will ask you to complete two questionnaires that will take about 30 minutes. These will help us to find out more about your child's physical activity and how they move. One of the questionnaires also asks about your child's social skills. There is strong evidence of a link between social skills and being active.



Session Two

This session will take place 1 to 3 weeks after the first session.

Your child will do the **Ignite Challenge** again with the same physiotherapist. You do not need to complete any questionnaires during this session.



Optional: Your child will have the option to take part in a 20-30 min interview with a Novita therapist. This will let you child talk about their experiences of physical activity and what they thought about taking part in the **Ignite Challenge**. This interview can happen at the end of the second session or on a further visit to Novita and will be audio-recorded (with your / your child's consent) so we don't miss anything they tell us.



Who is involved?

Kids and young people aged 6-17 years old living with ASD who would be able and willing to participate in 45-60 minutes of active games (with the assessor's guidance and without extra assistance from a parent) are being invited to take part in this project.

Our research leadership team includes lots of different people from Novita.



Kerry Evans is a physiotherapist and Novita's Practice Leader (Physical). She is leading this research and is also responsible for Novita's physiotherapy services and group programs for people living with ASD.



Professor Virginia Wright is a Physiotherapist and Senior Researcher from Holland Bloorview Kids Rehabilitation Hospital in Toronto, Canada. Virginia and her team developed the **Ignite Challenge** and she visits Novita for six weeks every year and partners with us on lots of research projects.



Penny Miller is a speech pathologist and Novita's Practice Leader (Developmental). She leads Novita's ASD services and will train and support our research team to work with young people living with ASD.



Dr Annemarie Wright is a physical activity and health professional and researcher. Annemarie will co-ordinate the research project. We will also work with other Novita therapists who will do the assessments and interviews.

What are the benefits of taking part?

If you and your child take part in this project the experience of doing so might help you to discover some new things about what motor skills they can do well, and what skills they find more difficult. This experience might then help you both to think about different goals to work on or different physical activities, games or sports to try. If your child is interested in providing us with feedback about the assessment, then this could benefit more young people by helping us to make sure it is fun for all kids and young people living with ASD.

Both **Ignite Challenge** assessments are free of charge as they are paid for by our research funding. You will receive a \$20 taxi/petrol voucher for attending each **Ignite Challenge** session. At the end of the second session your child will receive a \$20 gift card as a thank you for taking part. Kids or young people who also take part in an interview will receive a \$10 gift card as a thank you for the additional time spent doing this.

Are there any risks?

If your child doesn't do a lot of physical activity they might find that they get puffed out or tired when they complete some of the activities. They might also find that some of their muscles feel a bit sore for two or three days after the **Ignite Challenge** assessments. Both of these things are normal responses to physical activity. Our study physiotherapists will make sure your child can have a break for a drink or a light snack (that they can bring with them) at any time during the assessment. They can also give you some advice about how to recover well after being in this assessment or other physical activity.

The **Ignite Challenge** is designed for people aged 6-17 years old and the activities are all at different levels of ability. Even though some of the games are altered slightly depending on your child's age or ability, they might find some of them more difficult than others. This might cause them (or you) to feel a bit disappointed. Our study physiotherapist can give you general information about the different types of activities, motor skill intervention programs or groups that might support your child to develop these motor skills.

Please note that taking part in this study does not guarantee that you will be given any additional NDIS funding for any motor skills or physical activity intervention.